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ABSTRACT

The perceptions of burden in providing care to the disabled elderly by a family member may be affected by the caregiver's personal and social resources and by the differences in involvement and familial roles between the caregiver and the care receiver. To test this relationship, 41 spouse and adult daughter caregivers involved in a home-based treatment program completed the 29-item Zarit Burden Interview and a checklist of their participation level in 10 caregiving tasks, and rated the incidence and severity of the care receiver's specific behavioral problems. Adult children caregivers reported sources of burden which were outside the caregiver/care receiver relationship, with major stressors being the influence of concurrent role demands and financial strain. Spouse caregivers, on the other hand, reported sources of stress within the caregiving relationship, with major burdens being personal functioning, especially in direct caregiving tasks, and interpersonal relationships with the disabled spouse. These findings suggest that fundamental differences exist in how elderly spouses and adult daughters define and perceive their roles as primary caregivers. (ABB)

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FAMILY CAREGIVERS AND BURDEN: A DEVELOPMENTAL PERSPECTIVE

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FAMILY CAREGIVERS AND BURDEN: A DEVELOPMENTAL PERSPECTIVE

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Clinical studies identifying sources of burden among family caregivers have tended to focus on level of impairment. Recently, however, some research has begun to examine the contextual relationship of the caregiver to their disabled relative. The present study examined 41 spouse and adult child caregivers participating in a home-based treatment program to determine whether caregiver gender, residence or relationship to the client affected their involvement in providing care, level of burden or selection of treatment problems. Analysis of client demographic and clinical variables by caregiver groups revealed no significant differences. Similarly, number of problems identified, caregiver tasks performed and an overall burden score (Zarit Burden Interview) were not significantly discriminated by the caregiver variables. Nevertheless, spouse caregivers identified a greater number of target problems in the areas of personal care and task performance ($t=2.36$, $p<.03$; $t=3.16$, $p<.01$) and were more involved in personal care, meal preparation and dispensing medications (Fisher exact, $p<.05$) even though adult children reported higher burden from competing task demands ($t=-2.32$, $p<.05$). Implications are discussed from a developmental model of family stress.

Introduction

Of all the roles performed by the family, perhaps its most seminal involve care and nurturence (McGoldrick & Carter, 1982; Parsons & Bales, 1955). Data from several studies indicate, for example, that the presence of an interested family is the best single predictor of institutional placement with the elderly (Brody et al., 1978; Townsend, 1965). Thus, the family's ability to care for its elderly members may have a direct effect upon their residential status, which in turn, has been associated with longevity and quality of life (Tobin & Lieberman, 1976).

One variable hypothesized to be involved in family care of the disabled elderly is caregiver burden. This concept, however, would appear at best, vagely defined in the literature. Suffice it to say for the purposes of this paper, that a stress paradigm is usually adopted where burden is defined in terms of salient stressors and mediating variables. More importantly, these investigations have tended to focus on the caregiver/care receiver dyad (e.g., level of debility) despite caregiving being conceptualized as a function of the family system, in toto. Two concepts basic in expanding the contextual analysis of caregiver burden from a dyadic to family perspective are the caregiver's developmental roles and corresponding resources within the family.

Many members of a disabled elderly's immediate or extended family may assume the role of primary caregiver. Most commonly, it is their spouse and if they are unavailable, the onus of care usually falls to an adult female child (Cantor, 1983; Crossman et al., 1981). Family roles of adult female children have been characterized by their multiple and concurrent demands (Brody, 1985). The confluence of career aspirations, marriage or remarriage, child-rearing, and extra-familial commitments involve a considerable investment of personal time. By

comparison, the familial roles of the elderly reflect a reduction in concurrent role responsibilities. No longer are parenting and work the predominant tasks. Therefore differences in the number and quality of concurrent familial roles adult female children and elderly parents perform are hypothesized to affect how they define the caregiving role and identify sources of burden associated with it.

The personal and social resources of family members also change across the life course. Diminished physical abilities, opportunities for social interaction outside the family, and economic earning capacity have been associated with the normal aging process (Verwoert, 1981), Shanas (1979), for example, has noted the transition in relative importance of family relationships to the young, middle aged, and elderly. Thus the caregiver's personal resources and access to social supports in meeting familial responsibilities may effect their ability to cope with caregiving tasks and are therefore hypothesized as relevant factors in understanding caregiver burden.

The purpose of this paper is to test whether a significant relationship exists between familial status and level of involvement and perceptions of burden in providing care to the disabled elderly.

Subjects

Forty-one primary caregivers from the Elderly Support Project (Pinkston & Linsk, 1984) comprised the study sample. Thirty-two caregivers were elderly spouses and nine were adult female children. Mean age of spouse and adult child caregivers were 68 and 40 respectively. All spouse caregivers resided with their disabled spouse as did 6 of the 9 adult children. Twenty or 63% of the spouse caregivers were wives. Although these data were well controlled for the purposes

of the original study, the absence of data identifying the caregiver's roles and responsibilities outside the caregiving relationship was a limitation for the purposes of the present study. One advantage of using these data, however, was the extensive demographic and clinical information collected on the care-receiver providing an opportunity to examine its relationship to caregiver behavior.

Procedure

Caregivers were asked to complete the twenty-nine item Zarit Burden Interview (Zarit et al., 1980), a checklist of their participation level in ten caregiving tasks, and rate the incidence and severity of the care-receiver's specific behavioral problems.

Prior to the results of the analysis to be reported, the following coding and characteristics of the sample were determined.

(1) Seven subscales derived from the Burden Interview were developed based on conceptual issues hypothesized to be salient in a family stress model of caregiving. The subscales attempted to measure burden associated with the following sources:

- Competing task demands.
- Competing personal demands.
- Caregiver physical problems
- Caregiver financial problems.
- Caregiver/Care-receiver interpersonal-relational problems.
- Caregiver intrapersonal problems.
- and Caregiver perception that the care-receiver's needs were excessive (i.e., beyond what the caregiver felt was warranted).

(2) The care-receiver's problematic behaviors were classified into three categories: self-care, instrumental tasks, and relational.

(3) Reliability checks were performed on the burden subscales (inter-item reliability, Cronbach's alpha) and the problem classification categories (inter-judge reliability).

And (4) Caregiver groups (i.e., elderly spouse and adult child) and the care-receiver's age, race, gender, residence vis-a-vis the caregiver, level of income, self-care abilities (Shanas Self Care Inventory), and mental status (Kahn Mental Status Exam) were not significantly related (Fisher's Exact Test, Student's t-test).

The analytic procedure involved the following: Application of Student's t-test to determine which of the burden subscales and target problem categories were significantly discriminated by the primary caregiver's familial status and calculation of Fisher Exact Test probability coefficients to determine if similar relationships existed between caregiving tasks and the caregiver groups. Zero order correlation analyses between burden scores and incidence of target problems by caregiver groups to determine how this aspect of the caregiving relationship affected elderly spouse and adult child caregivers. And an analysis of higher order coefficients to eliminate positive findings due to statistical artifacts (e.g., multicolinearity).

Results and Discussion

Mean ratings of burden by caregiver groups are presented in Graph 1. Inspection of this Graph revealed adult female children rated burden associated with competing task and personal demands higher than elderly spouse caregivers who, in turn, rated burden associated with physical, financial, and their interpersonal relationship with the care-receiver higher. Even though competing task demands was the only subscale to reach statistical significance, the trend across the burden measures

would suggest that adult female children experienced greater burden due to the confluence of outside role responsibilities and caregiving while spouse caregivers reported greater burden due to the interaction of personal abilities and their interpersonal relationship with their disabled spouse. Data presented in Graph 2 indicate elderly spouse caregivers were more likely to identify deficits in self-care and task behaviors as treatment problems while adult female children presented relational problems. Regression analysis of target problem identification and burden by caregiver groups, however, revealed that problems requiring provision of care (e.g., task problems) were associated with adult caregivers reports of burden (financial) while relational problems were related to spouse caregiver reports of burden (physical). Level of involvement in caregiving tasks are presented in Graph 3. Results indicate that elderly spouse caregivers were significantly more involved in providing assistance with personal care, meal preparation, and dispensing medications. In addition, assistance with housekeeping and providing supervision almost reached statistical significance.

In summary, adult female children were less involved in the direct care of their disabled parent, yet reported greated burden associated with competing demands outside the caregiving relationship. In addition, burden (financial) for these caregivers was significantly related to the care-receiver's inability to perform instrumental tasks despite adult children identifying more relational problems than elderly spouse caregivers.

Elderly spouse caregivers reported greater participation in the care of their disabled spouse, especially tasks requiring repeated or intense involvement. Sources of burden represented aspects of their own personal functioning or interpersonal relationship with their disabled spouse. Finally, elderly spouse caregivers

reported burden (physical) associated with relational problems even though they identified significantly more self-care and task target problems when compared to adult children.

Conclusion

Results from this study suggest fundamental differences exist in how elderly spouse and adult female children define and perceive their role as primary caregivers. The influence of concurrent role demands was predicted to be a major developmental stressor for adult female children. Findings presented in Graph 1, of competing task and personal demands, would be consistent with this experience. In addition, subsequent regression analyses of data presented in Graphs 1 and 2 revealed financial burden was significantly associated with deficits in the care-receiver's instrumental functioning (i.e., task behaviors). These findings are also congruent with the study's conceptual model as one would predict adult female children to experience greater financial strain in caring for their disabled parent due to lost work hours or additional costs in securing alternate care arrangements. The sources of burden for adult female children are therefore conceptualized as outside (i.e., external) the caregiver/care-receiver relationship, per se. Neither the level of caregiving participation nor the caregiver's personal abilities appeared problematic. Rather, the total sum of roles and responsibilities associated with the mid-life phase of adult development, of which care to a disabled parent may be one, were found to be salient in understanding the experiences of these caregivers.

When compared to adult children, spouse caregivers identified sources of burden, albeit statistically nonsignificant, related to personal functioning and their interpersonal relationship with their disabled spouse. These findings would be consistent with a developmental model that posits diminished physical, social, and economic resources as primary issues in later stages of the life course. Findings

in Graphs 2 and 3 also suggest that these caregivers were more attuned to the daily needs of the care-receiver and more involved in their direct care. Increased awareness and involvement by spouse caregivers would be expected given the reduction most elderly members experience in concurrent role responsibilities outside the family system and shifts in role status within the family. Hence, the sources of stress in elderly spouse caregivers are conceptualized to reside primarily within the caregiving relationship.

It would be overly simplistic to conclude, however, that caregivers will always report similar stressors and sources of burden on the basis of their familial status. Individual variations in the caregiver's personal attributes and social supports as well as the level of impairment in the care-receiver will continue to remain important. Nevertheless, results from this study clearly suggest that developmental issues are salient in increasing our understanding of caregiver burden.

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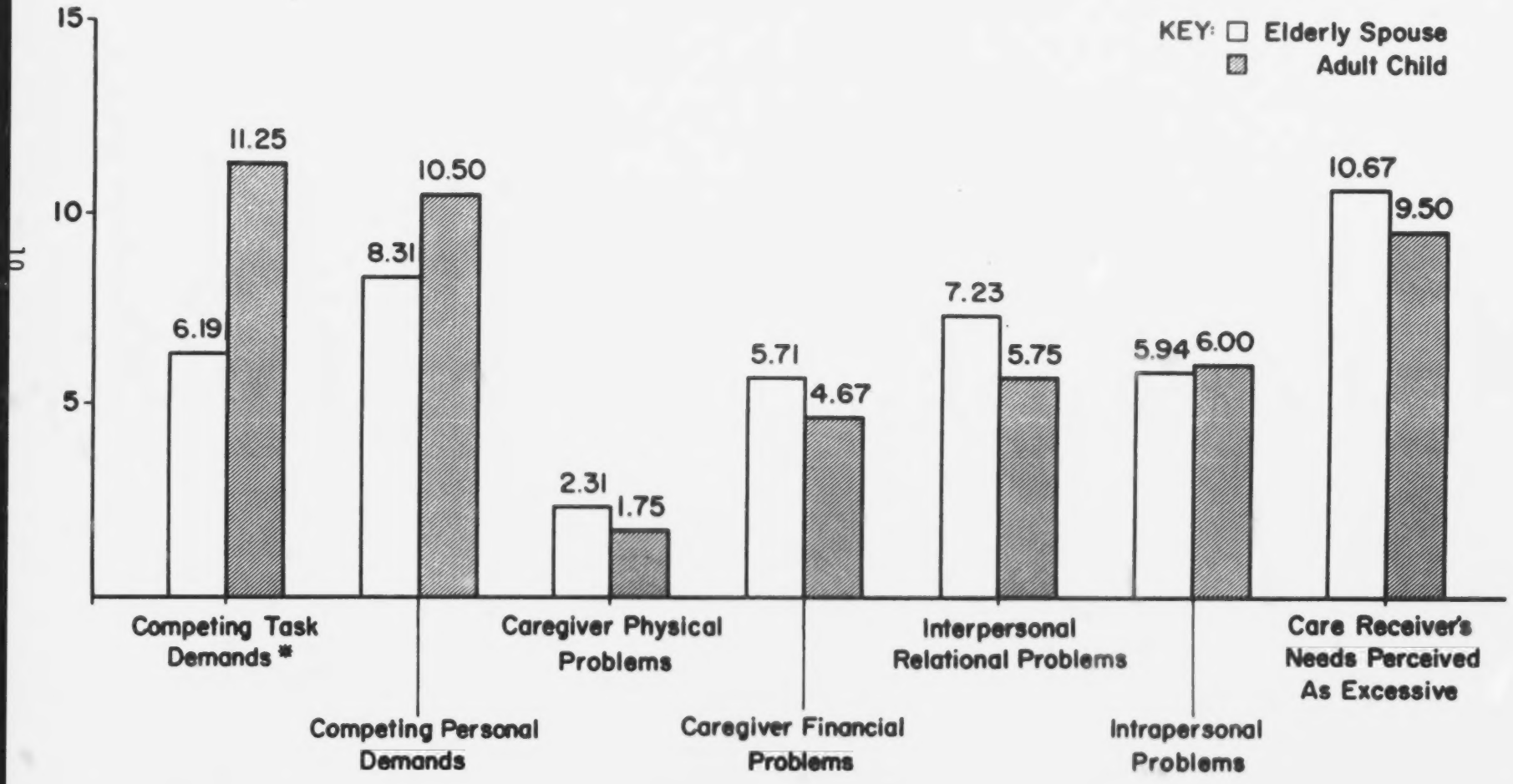
GRAPH 1

Mean Reports of Burden by Elderly
Spouse and And Adult Child Caregivers

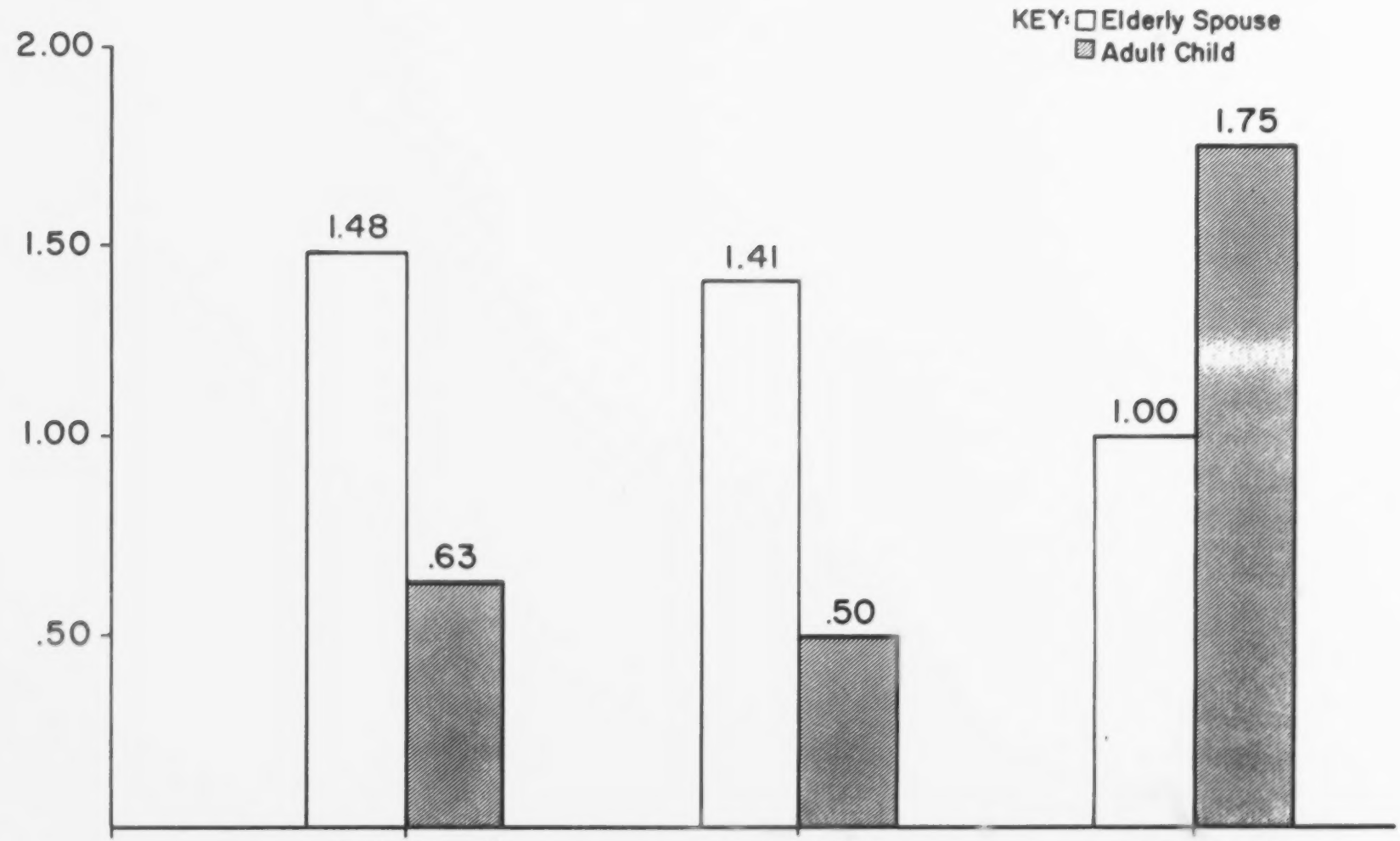


*p<.05

Burden Subscales

GRAPH 2

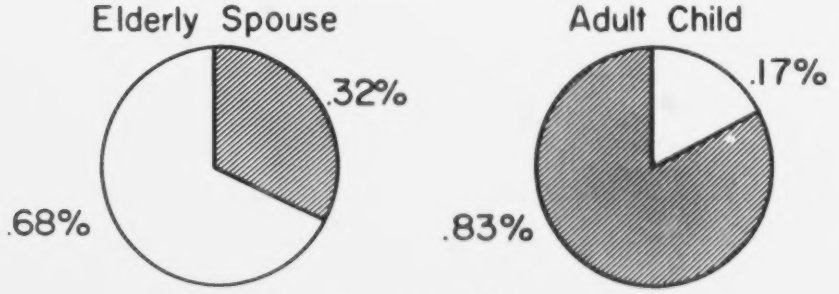
Mean Number of Target Problems Identified
by Elderly Spouse and Adult Child Caregivers



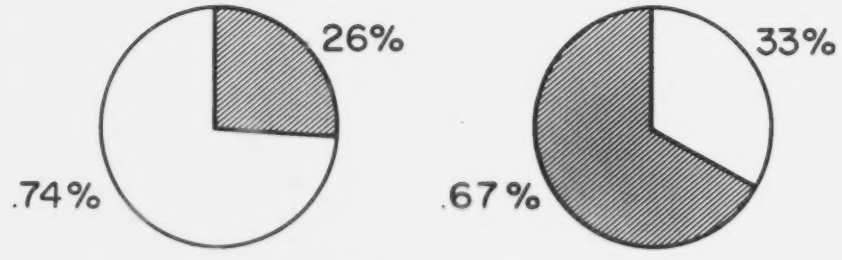
*p<.05
**p<.01

GRAPH 3

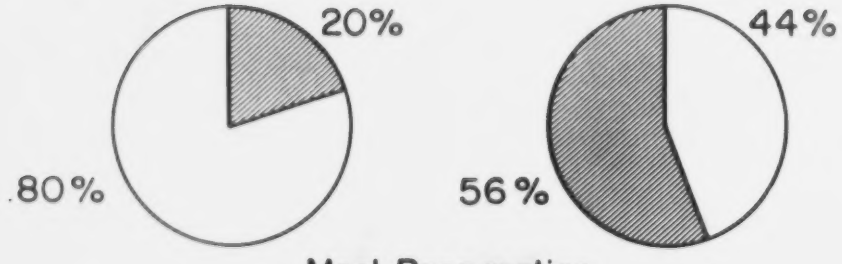
Level of Involvement in Caregiving Tasks by Elderly Spouse and Adult Child Caregivers



Personal Care
FET p=.03



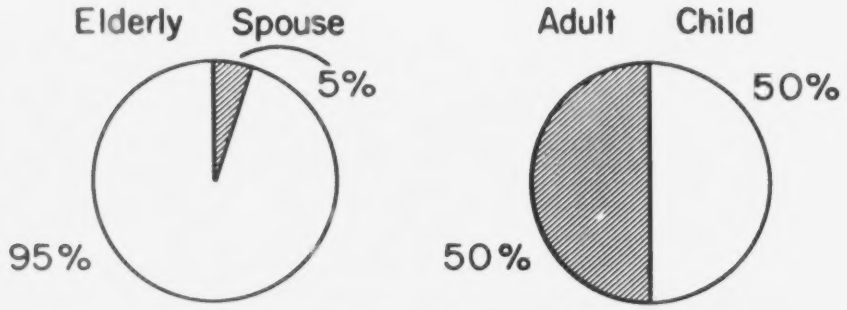
Supervision
FET p=.08



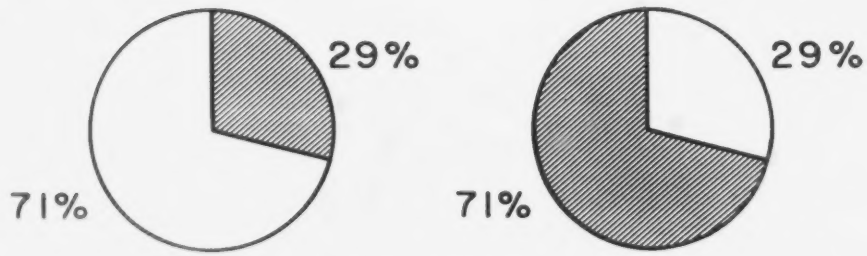
Meal Preparation
FET p=.03

KEY: ☐ By Self
▨ Shared; Others performed

GRAPH 3 continued



Dispense Medications
FET p = .01



Housekeeping
FET p = .06

Daily Checks
FET p = .41 KEY: ☐ By Self
▨ Shared; Others performed

GRAPH 3 continued